Learning Disabilities Mortality Review (LeDeR) Programme

# Briefing Paper 11: How reviewers will work with you after the death of your relative with learning disabilities

## Introduction

We have written this guide to tell you about the Learning Disabilities Mortality Review (LeDeR) process and how you can be involved. Towards the end of the leaflet you will find some questions and answers. If you need further information please contact the LeDeR team (tel: 0117 3310686) and if appropriate they can put you in touch with someone locally.

The Learning Disabilities Mortality Review (LeDeR) programme has been set up to improve the quality of health and social care for people with learning disabilities. It does this by supporting local areas to carry out reviews of the deaths of people with learning disabilities. The process draws attention both to good practice and to potentially avoidable problems with care and treatment. Reviews make recommendations about how services could be improved if relevant.

The LeDeR progamme encourages reviewers to involve families throughout the whole review process, or as much as families feel able or want to be involved. As a family member, you are likely to have the greatest knowledge of the person who has died, to know a great deal about their care and support, and be able to help us understand the sequence of events leading to your relative's death. Your unique perspective can tell us what could make a difference to the lives of other people with learning disabilities.

We know this will be a sad and difficult time for you but hope you will feel able to take part. You will be treated with sensitivity and respect, and invited to make recommendations based on your experience.

## About reviews

The review of your relative's death is part of a national process looking into deaths of people with learning disabilities. It is not a sign that there are any concerns about the treatment or care of your family member. It is important to remember that the reason for reviews is to share good practice and learn what could help improve services for people with learning disabilities. Your opinions about this are very important and the reviewers will want to hear about them.

## Stages in the review process

**Notification**

All deaths of people with learning disabilities aged 4 years and over are reported to the LeDeR programme.

The person notifying us of a death completes a set of standard questions. After this, a reviewer undertakes an initial review of the death.

**Initial Review**

To complete the initial review the reviewer:

- Checks the information received at the notification stage.
- Reads relevant extracts from case notes.
- Talks to a family member or someone who knew the person well, and/or professionals involved with their care.
- Writes a 'pen portrait' of the person who has died.
- Writes a timeline of the events leading up to their death.
- Decides whether a multiagency review (see below) should happen.

If you have been contacted this is either because your details were given when LeDeR was notified of your relative's death or because we have learnt later that you may be able to help with the review of their death.

The reviewer will tell you about the LeDeR mortality review programme, its aims and purpose, and ask if you would like to be involved in the review of the death of your relative.

- If you have said yes, the reviewer should make an appointment to speak with you and send you the LeDeR programme information. See Preparing for the Initial Review below.
- If you have said no, this is fine, but the reviewer may still offer to send the information in case you want to be involved at a later stage or to get feedback from the reviewer once the review is complete.

Discussing the circumstances leading up to a person's death with someone who knew them well really helps the reviewer to understand the person and anything that may have contributed to their death, as well as any good practice in their care and support. The reviewer may ask you about the person's likes and dislikes, their health, the environment in which they lived and the services they received.

**Preparing for the Initial Review**

When they speak with you, to help you feel prepared for the meeting, the reviewer may:

- Tell you what they want to find out at the initial review (and, if you like, let you have a blank copy of the paperwork they need to complete).
- Say what information they hope you will feel able to share with them and what will happen to that information.
- Remind you that you can rearrange or stop the meeting at any time.
- Tell you about the possibility of a further, multiagency review (see below).

We expect reviewers to

- Be empathic and supportive so you feel safe and know that what you share with them is valued and useful.
- Try to answer your questions, and give suggestions of who else may be able to help you if they cannot.
- Let you know they will be happy to explain any terminology you don't understand.

- Explain what to do if you have a complaint about something that has happened, so that you can follow this up with someone who has the right knowledge and experience.
- Discuss if and how you would like feedback from the initial review and whether you want to be involved in a later multiagency review if the initial review indicates this is needed. (This could mean you attending a multiagency meeting or contributing to the meeting in another way).

**Multiagency Reviews**

A reviewer may arrange a multiagency review if:

- They believe a fuller review of a death will lead to learning that could improve practice.
- They think potentially avoidable factors contributed to the death.

A multiagency review is a chance for people involved in the care of your relative to discuss the circumstances that led to the person's death, identify any potentially avoidable contributory factors and any best practice in relation to their care, make any necessary recommendations and agree an action plan.

Anyone who is going to attend a multiagency review meeting will be sent copies of the pen portrait, timeline and description of circumstances leading to death that were drafted after the initial review. They will be asked to add any relevant comments and return these to the reviewer so they can be updated and sent to everyone before the multiagency review meeting. Comments could be to do with the initial diagnosis and management of any illnesses; whether there was any notable best practice or anything of concern; if there were reasonable adjustments made to help the person to receive appropriate care and treatment etc).

Fresh information may also be available through the reviewer requesting a copy of additional notes relating to the person.

**Preparing for a multiagency meeting**

If there is to be a multiagency review meeting, the reviewer will contact you (providing you have agreed that you would like to be involved) and discuss whether you would like to attend. They may explain who will be present (their names and roles) and will outline what will happen so you know what to expect from the meeting. If you don't want be there you can still contribute by providing additional information for the reviewer to present at the meeting.

To help make it comfortable for you to attend and join in fully at a multiagency review, the reviewer should:

- Find out when and where it would suit you to have the meeting and try to fix the date, time and venue around key individuals/agencies if it is not be possible to suit everyone.
- Check with you what support you think you will need.
- Discuss and agree what needs to happen during the meeting if you don't understand what is being said, get upset or angry at any point.
- Make sure that the others attending the meeting are aware that a family member will be attending.

Along with others who are attending the multiagency review you will be sent the most up to date pen portrait, timeline and description of events leading up to your relative's death, if possible a week before the meeting.

**At the multiagency review meeting**

The Chairperson (usually the reviewer) will introduce everyone and describe the purpose and structure of the multiagency review. They will keep the emphasis of the meeting on what can be learnt to improve services while the group addresses the key questions noted in the initial review.

They will make sure everyone present feels able to contribute by:

- Being careful about the use of jargon and terminology.
- Being aware of the emotions of people in the room.
- Allowing sufficient time for everyone to speak.

People need to be as honest and open as possible at a multiagency review meeting, so the meeting should not be a place where blame is given or be seen as an ordeal by those present. However please be assured that if poor or unsafe practice is identified it will be reported to the Local Area Contact and investigated by the relevant authority.

At the end of the meeting it should be agreed how families who are not present will receive feedback if they have asked for this.

## Questions and answers

**Who does reviews?**

All reviewers have been trained in how to conduct a review of a death of a person with learning disabilities. They all have a background in health or social care. They are all supported by a Local Area Co-ordinator.

**Who else is involved "locally"?**

The LeDeR programme expects each NHS sub-region to have a local Steering Group to guide the implementation of the programme locally, monitor action plans resulting from local reviews of death and take action as a result of information obtained from local reviews. There should be family representation on the local steering group.

**What about confidentiality and data protection?**

The LeDeR programme has Section 251 (of the NHS Act 2006) approval to use patient identifiable information so that the deaths of people with learning disabilities can be reviewed. Because of this, health and social care staff can be confident that the work of the LeDeR programme has been scrutinised by the national Confidential Advisory Group (CAG). It means that health and social care professionals can share identifiable information without consent, both in the notification of deaths of people with learning disabilities, and for contributing to reviews of their deaths.

**If these reviews are happening locally across the country what is happening nationally to make sure lessons are learnt?**

Notifications of death, and the reports of the reviews of deaths, are submitted to the central LeDeR programme team at the University of Bristol on an ongoing basis. The central LeDeR programme team brings this information together nationally to report on common themes and recommendations that will improve service delivery for people with learning disabilities and their families. NHS England has set up a 'Learning into Action' group to take forward actions nationally.

**What should I do if I am bothered by something that happens during a review?**

You should let your local reviewer know. If you would find this difficult because it relates to them, please call the central LeDeR team office (tel: 0117 3310686) and they will let the relevant local area contact know.

**Can I contact a reviewer later if I think of something else after a review?**

Yes, please do. Your views are important and we understand that you might think of some things at a later stage.

**Will there still be a review if another investigation into the death is also taking place?**

Yes. Although the different bodies will conduct their investigations in a cooperative manner, each review will have its own process and focus of attention.

**What happens after reviews?**

After each initial or multiagency review, the reviewer completes a list of recommendations for service improvements. These are reviewed by each Local Area Contact and by the local Steering Group. Recurrent themes and significant issues are identified and addressed at national, regional and local levels.

The LeDeR programme collates common themes and recommendations from reviews and shares those in anonymised format with local Steering Groups. These are summarised in the LeDeR programme annual reports available to the public.

**Will families automatically be informed of the review process even if they haven't had involvement with the person who has died for a long time?**

Not necessarily- it will be up to the reviewer to make the decision based upon the information that they have gathered during the review. However they should consider how the family might feel if they are not invited.

**What happens if the person who has died has indicated that they don't want their family involved in their care?**

Reviewers should try to explore the context of why and when the person who has died indicated this and make a decision based upon the information they receive. If for example, there have been ongoing safeguarding issues with the family, it may not be appropriate to include them in the review process.

If, on the other hand, the comment was made and recorded some years ago and the family have been involved with the person more recently, reviewers may feel justified in putting this aside.

**What does legislation and guidance say about staff (including reviewers) talking with families?**
Section 11 of the Health and Social Care Act 2001 places a duty on NHS organisations to involve and consult patients and the public in:

- Planning services that they are responsible for.
- Developing and considering proposals for changes in the way those services are provided.
- Decisions that affect how those services operate.

NHS England's '*Commitment to Carers*'[1] (2014) guidance echoes the requirements of the Care Act to place carers centrally in any consideration of a person's care. It also set out the need to review existing processes to gather bereaved carers' views on the quality of care provided to their relative in the last three months of life in order to help address gaps in evidence.

Regulation 20 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 reports Duty of Candour regulations. These clearly state that NHS bodies (or those acting on their behalf) have a duty to promptly notify and offer an explanation and apology for incidents that have caused people harm. Reviewers should be aware of Duty of Candour protocols and procedures in your areas.

The NHS Constitution (2015) states that NHS services 'must reflect, and should be coordinated around and tailored to, the needs and preferences of patients, their families and their carers'. It goes on to stress that staff should 'be open with patients, their families, carers or representatives, including if anything goes wrong, welcoming and listening to feedback and addressing concerns promptly and in a spirit of co-operation.'

In 2018 the National Quality Board provided guidance about how NHS trusts and foundation trusts should engage, and work effectively with families following a death. The guidance is accompanied by a leaflet offering information for bereaved families [2].

[1] NHS England 2014 'Commitment to Carers'. Available from: https://www.england.nhs.uk/wp-content/uploads/2014/05/commitment-to-carers-may14.pdf
[2] National Quality Board 2018 National guidance for NHS Trusts engaging with bereaved families. Available from: https://www.england.nhs.uk/ourwork/part-rel/nqb/national-guidance-for-nhs-trusts-engaging-with-bereaved-families/